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ABSTRACT

This guide examines the evolution of human services systems toward the recognition that individuals with handicaps can make consumer choices and should be included in decision-making sessions. Consumers with disabilities are seeking empowerment through their presence and participation in political processes and community events. Choices regarding housing, employment, and other aspects of life cannot be made by a professional on behalf of disabled persons. Quality of life issues should be incorporated into research of the life settings of individuals with disabilities. Findings from existing research indicate that more joint planning with consumers is needed, and ways that the service sector can get consumers involved are considered. The Consumer Job Satisfaction Scale, being developed by the National Association of Rehabilitation Facilities, is presented as a tool to assess factors contributing to quality of working life. Techniques for measuring satisfaction in nonverbal individuals are also addressed. Implications for consumers, state and federal agencies, and rehabilitation service providers are examined. (47 references) (JDD)

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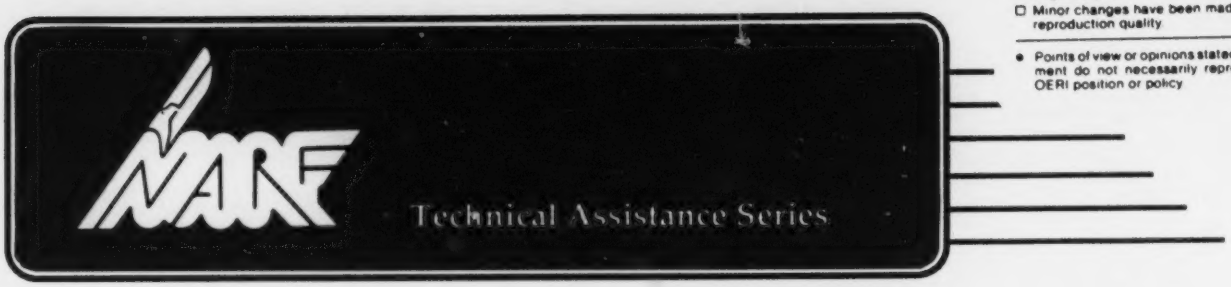

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Consumer Choice and Satisfaction

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Consumer Choice and Satisfaction

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Foreword

The NARF National Scope Supported Employment Demonstration Project has contemplated the measurement of consumer choice and satisfaction for the past three years. This document is based on our direct experiences measuring consumer choice for our review of Exemplary Practices (NARF, 1989a).

Our experiences lead us to believe that a brief interview format that can be completed in 30-40 minutes could assist with attaining information directly from consumers. The result of our efforts is the **Consumer Job Satisfaction Scale,** currently available from NARF for field testing. That scale follows the guidelines covered in this document. Rehabilitation providers are reporting that the instrument is helpful in providing a way to directly measure job satisfaction and plan for future activities.

NARF salutes those who have worked long and hard to bring consumer satisfaction to the forefront! NARF also wishes to thank those who worked for the passage of the Americans with Disabilities Act. Such efforts should go far to enhance the everyday lives of many citizens in our country.

When envisioning possibilities for greater consumer choice and satisfaction, we encourage you to stretch "the limits." We encourage you to put consumer choice and satisfaction at the top of your list, to make it a priority, and to proceed quickly to make dreams, rather than limitations, a reality.

Acknowledgments

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CONSUMER CHOICE AND SATISFACTION

A historical examination of the quality of life for people with disabilities in some ways may be better suited to an epic film on the distortions of reality than to chronicles of scientific inquiry or to the narrative accounting of the accomplishments of a sophisticated civilization. Such a historical examination may also be better suited to science fiction, the mad scientist gone awry, than to the current document--an analysis and policy recommendations regarding consumer choice and satisfaction.

The recent film, "My Left Foot," for example, vividly portrays the difficulties encountered by a person with severe physical impairments and only limited speech. Although Christie Brown lives in Ireland, he shares an almost universal frustration with other individuals with similar impairments and it is only through his persistence that he has taught the world how much he has to communicate and demonstrated his writing and artistic capabilities.

For some reason, throughout history people the world over have chosen to assume that individuals with disabilities have less cability and greater disability than is actually the case. This "falsification" of reality continues up to the present time and can be predicted to extend into the future. One has to marvel at the tremendous achievements some individuals with disabilities have made. Stephen Hawking, the renowned physicist, in the introduction to his recent book, A Brief History of Time: From the Big Bang to Black Holes (1988) has eloquently addressed the reality of being disabled:

> Apart from being unlucky enough to get ALS, or motor neuron disease, I have been fortunate in almost every other respect... I was again fortunate in that I chose theoretical physics, because that is all in the mind. So my disability has not been a serious handicap...
>
> I had to have a tracheostomy operation which removed my ability to speak, and made it almost impossible for me to communicate...However, Brian not only helped me revise it (this book) he also got me using a communications program called Living Center which was donated to me...With this I can write books and papers, and speak to people using a speech synthesizer... The synthesizer and a small personal computer were mounted on my wheelchair by David Mason. This system has made all the difference: In fact I can communicate better now than before I lost my voice...

> I'm grateful to my assistants...and my team of nurses. None of this would have been possible without the support for my research and medical expenses that has been supplied by Gonville and Caius College, the Science and Engineering Research Council, and by Leverhulme, McArthur, Nuttfield, and Ralph Smith Foundations. (p. vii)

Such a listing tells the tale of the elaborate arrangements that often must be made for people with disabilities to access needed supports.

While institutions in their time served the radical purposes of furthering the lives of individuals with disabilities, still these institutions were established based upon a focus on the "dis"abilities of the individuals they served. From the era of neglect, to the imprisonment in insane aslyums or the protection afforded by placement in large institutions, societies have continued to assume the worst. If an individual couldn't speak, he or she was assumed to be "stupid." If a person had difficulty reading, he or she was assumed to be retarded. If a person were retarded, it was assumed that he or she couldn't live independently, contribute to the labor force, or be a part of the larger community. And so it has continued.

Although human service systems have evolved and sophisticated educational systems are now in place, our collective ignorance prevails. People with disabilities continue to be segregated and exploited, whether it be further maiming in India to enhance the lucrative proceeds going to the "manager of the beggar" or whether it be the continuance of rehabilitation systems to enhance the status of the provider and not dedicated first and foremost to the individual. Farber (1968) has described systems which are designed to be self-perpetuating. The rehabilitation system certainly has exhibited many of the characteristics of a system designed to insure the survival of its managers. However, the era of the Americans with Disabilities Act is signaling change.

As early as the mid-seventies with the establishment of The Association of Severe Handicaps (now called the Association for Persons with Severe Handicaps), people began to recognize that individuals with severe handicaps could learn and that a system of advocacy and greater access to education and training were in order. From the mid-seventies to the current time, researchers have marveled at the abilities that have been uncovered when we have organized our education effectively. As Ogden Lindsley has stated, we have realized that it was "our ignorance and not theirs."

In the seventies, a group of professionals, working closely with individuals with severe disabilities, began to understand that the laboratory research of Murray Sidman on

the discrimination skills of individuals with autism and severe retardation could assist with the training needed to cope with practical everyday events. Thus research evolved from circle ellipse discriminations to block sorting and bicycle assembly ala Marc Gold's famous "try another way."

Many contributions were made along the way by persons such as Rob Horner who presented case by case scenarios describing the features needed to achieve skill generalization. The group of educators and researchers began to talk of generalization across environments or generalization across persons, places, and things. As research evolved further, it became obvious that "training in the community" or training at a specific site for a specific skill was much more effective than previous strategies of classroom instruction with assumed generalization.

From the era of Education for All and right to education/ treatment came the development of community living, deinstitutionalization, and the evolvement of teaching simple skills fundamental to securing jobs in the community. At last as the eighties come to a close and we enter the nineties, we have achieved gigantic gains. Persons once shunned and set aside are now functioning interdependently as full contributing members of society. Persons who previously were dependent on the welfare of the social security system are now paying taxes and contributing to the overall gross national product.

During the past fifteen years some parallel movement has occurred within the rehabilitation community. Between 1950 and 1985, as individuals with developmental disabilities were deinstitutionalized, they began to be trained through sheltered workshops and started earning wages for the first time. These programs were funded through state mental health/mental retardation and developmental disabilities agencies. Although the vocational rehabilitation system was initially designed to serve veterans returning from war or adults suffering work-related injuries, the system now has been modified to serve adults with developmental and other disabilities.

Today individuals with such disabilities as long-term mental illness and traumatic brain injuries are being served through the rehabilitation system, although recent evidence suggests that much more facilitation is needed to truly enhance rehabilitative efforts for these populations (Tashjian, Hayward, Stoddard, Kraus, 1989). Tashjian et al. report that 39 states currently have interagency cooperative agreements between vocational rehabilitation and mental health agencies, and that many procedural changes could improve cooperative service provision.

From this background has emerged a rallying cry for "full rights and equal status" for people with disabilities. The civil rights era for people with disabilities has resulted in the Americans with Disabilities Act as well as people with disabilities speaking out for themselves and being heard. At long last, consumer choice and satisfaction are being addressed.

Today people with disabilities are speaking out and being heard. Individuals who can't talk are using electronic communication systems to express their needs, interpreters are assisting persons with limited hearing, and personal care attendants are accompanying persons with physical disabilities into the community. Their consumer choice is to make decisions for themselves, to be included in important decision making sessions, and to change systems so that their input will be guaranteed. In short, consumers are seeking and securing empowerment.

Presence and Participation

Consumers now are seeking empowerment through their presence and participation in important political processes and through their presence and participation in normal events occurring in the community. In January 1989, the Office of Special Education and Rehabilitative Services hosted a conference on Self-Determination (Perske, 1989). Participants, many of whom had disabilities, came up with 29+ recommendations. Some of the recommendations which are most pertinent to consumer choice and satisfaction are the need for:

- All government policy making functions to establish as a top priority the "enabling of people with disabilities to determine their own futures."
- A program for reshaping professional attitudes be instituted for those already working in the field.
- Persons with disabilities to be provided formal courses in self-assertion.
- Persons with disabilities to be involved in his/her own program planning sessions.
- Funding a series of model programs that exemplify self-determination attitudes and practices.

Empowerment has been highlighted as a key issue for the next few years in such documents as A Special Report to Grantmakers on Empowering People with Disabilities (JM Foundation, Robert Wood Johnson Foundation, & Pew Charitable

Trusts, 1989). That document stressed placement of persons with disabilities:

- on program advisory councils,
- on boards of directors, and
- in leadership positions.

Furthermore, leadership training activities have been suggested. Ludlow and Herr (1988) have recommended the need for corresponding supports, including access to generic community services, establishing a legal right to habilitation, and systems advocacy at the federal, state, and local levels.

Other reports (Schwier, 1990; Johnson & Fawcett, undated; the Premier's Council, 1989) have called for greater consumer involvement in the individualized planning process; consumer feedback concerning program effectiveness and satisfaction; and equal participation in community life. D'Aubin (1989) has provided a written record of the problems and experiences adults with long-term mental illness encountered in institutions. A primary message is that regulations and policies often have been in conflict with personal needs and concerns.

Home Living Concerns

Landesman (1986) has reported upon the results of her investigation into the match of availability of resources, the demands of the environments, and ability of individuals to perceive and to respond to environmental resources and demands.

According to Landesman's investigation, residents with more severe and stereotypic behaviors tended to regress over time regardless of setting; there was a general lack of large behavioral changes among residents; and increased staffing did not result in greater interactions among staff members and residents.

Schalock and Start (1988) also have provided insights into future residential considerations, suggesting that <u>environments can adapt to people with disabilities rather than always working for the individual to adapt to the environment</u>.

Heal (1988), in a review of client satisfaction found that

> Clients' satisfaction with their living situations may be the most neglected outcome measurement of residential placement, and yet it is perhaps the most important. (p. 218)

In a study conducted by Birenbaum and Seiffer (1976) of a large community residential facility, client satisfaction was assessed by asking direct questions and rating consumer responses as positive, negative, or neutral. The first phase of questioning focused on favorable and unfavorable aspects of the clients' placement.

Consumers also were requested to express their attitudes toward the residential facility. The overall response in the first and a second follow-up interview was mostly positive. The final interview (after 16-20 months), showed an increase in the neutral and negative responses and a slight decrease in the positive responses. This shift in attitudes was apparently the result of the consumers' desire to move to a more independent living situation.

Further study (after 40-44 months) found that 57% of the residents questioned wanted to move elsewhere--26% to apartments, 21% to parents, and 10% to foster homes (Birenbaum & Re, 1979).

Burchard, Hasazi, Gordon, Yoe, and Simoneau (1986) compared residents from group homes, natural homes, and supervised apartments. In this study, Burchard et al. discovered that apartment living created a greater feeling of satisfaction in comparison to natural and group home settings. Satisfaction was related to normalization of the clients' life-style and with the performance of independent of living skills.

Novak, Heal, Pilewski, and Laidlaw (1980) have utilized a Residential Satisfaction Scale (RSS) to assess satisfaction. The RSS contains 50 items that questioned satisfaction with residence, the community setting, and associated services. One result of their investigation was that satisfaction was notably higher for apartment settings versus intermediate care facilities.

Heal, Novak, and Chadsey-Rusch (1982) developed the Lifestyle Satisfaction Scale (LSS). This scale includes 29 items selected from the 50 used in the Residential Satisfaction Scale (Novak et al., 1980) through cross validation to a new sample of 39 subjects. With the LSS, total satisfaction is assessed along with specific satisfaction in four independent areas: (1) home, neighborhood, and community (nine items), (2) friends and free time (six items), (3) services (seven items), and (4) employment (one item). One unique and useful feature of the scale is an acquiescence subscale. This allows adjustments in scores for individuals who tend to say "yes" to whatever question is asked of them.

While many studies demonstrate that measures of residential satisfaction can be obtained for adults with developmental

disabilities, the studies have a "common shortcoming." Heal (1988) summarizes the shortcoming in the following:

> Most residents who have participated in these studies and in most community placements have been mildly and moderatley retarded individuals with sufficient language skills to be interviewed. If all retarded citizens are to have a "voice" in their destiny, then methods of measurement must be developed to assess the satisfaction of individuals who lack language skills. (p. 221)

Regarding residential preferences of persons being treated for a serious mental illness, many persons live with their parents; this usually is less than an ideal situation. The parents' role in the recovery process should not be that of caregiver; unfortunately, it often is the only option. Obviously, consumer choice is not accommodated through such a lack of alternatives. Such a living situation does not promote family unity. In fact, this situation may have a negative effect by preventing the individual with the mental illness from integrating into the community. As Thomas Posey (1990) points out,

> If a person wants to continue to live with his or her parents, it must be out of the free choice of all parties involved and not out of necessity or lack of other options. (p. 3)

Choices regarding housing cannot be made by a professional on behalf of the person with the disability. Choices should be based on the individual's input. The person's own perception is what determines success and satisfaction in a particular setting (Coulton, Holland, & Fitch, 1982; 1984). Consumers have definite housing preferences and the vast majority prefer typical housing to residential treatment settings (Ridgway, 1988).

One alternative to assist with meeting consumer preferences is supported living. In a supported housing setting, the center of control shifts from the staff to the consumer. The consumer "carries the keys" and can make decisions concerning his or her life-style and daily routines. Consumers may have staff members assist them in structuring their time and in developing positive daily activities, but the consumers make decisions about how their time actually is spent.

Employment Issues

Improved quality of life is one of the foremost reasons behind supported employment (Wehman & Moon, 1988). Yet, although measure of integration, wages, and benefits have been utilized and have been assumed to result in an "improved

quality of life," the research regarding the quality of life of persons employed through various models of supported employment as well as persons employed in sheltered workshops has been far from definitive. Additionally, little attempt has been made to systematically incorporate structured decision making by persons with severe disabilities into career, community, and residential planning processes.

A serious issue which has not been adequately examined is the disruption of existing relationships and supports when persons move from sheltered workshops into community employment (Nisbet & Hagner, 1988). As Nisbet and Hagner state:

> If this dimension is overlooked, supported employment efforts may fail due to factors other than the ability to work. Informal interactions in and out of the workplace provide a substantive base of support for persons with or without disabilities. (p. 262)

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ADDITIONAL THOUGHTS

At a recent conference the following messages were heard:

> People with disabilities are the poorest of the poor... we need to link up with the anti-poverty community. (Ames-Zierman, 1990)
>
> Quoting Greta Garbo, "They don't want to be alone, but to be let alone." (Nirje, 1990)
>
> You need to use your power to strengthen theirs, to enable them to have more power. (Nirje, 1990)

This past year, the state DD councils interviewed over 13,000 consumers with developmental disabilities and found out "only 20% work full-time." In some states consumers have been on waiting list up to 7 years. More than 50% of consumers report being lonely, compared to 25% of the general population. Consumers also desire greater independence and better wages: 90% of those surveyed made less than $9/hour, the national average. (McFadden, 1990)

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ARRIVING AT QUALITY

So how do we get there? Advice to the field follows.

The "Quality of Life Project," was funded by the Administration on Developmental Disabilities (Goode, 1988) to create a research-based agenda about QOL issues, enhance direct consumer involvement in agenda settings, and achieve consensus about QOL guidelines in major life settings made the following recommendations:

Regarding Measuring Quality of Life

- Develop client-centered instruments and procedures to determine individual QOL needs.

Regarding Planning

- Link planning to QOL outcomes for individuals.
- Gather additional input from consumers.
- Redefine the entire concept of service provision around individual needs with QOL as a service outcome.

Regarding Implementation

- Enhance QOL of persons with disabilities by developing peer counseling programs that match persons with disabilities who are productive, independent, and integrated with individuals who are less so.
- Train direct care staff to support persons with disabilities and their families in ways which enhance QOL.

Regarding Evaluation

- Design program evaluations that are QOL-oriented, have high consumer participation, and are useful to providers.

The state of Minnesota has spent time and energy reviewing historical developments for individuals with disabilities, gathering information on their current educational and community status, developing alternatives, and revising expectations for them and for funding agencies and provider communities. A New Way of Thinking (Governor's Planning Council on Developmental Disabilities, 1987) summarizes this

information as well as formulating new policy positions, stating that people need:

- To be seen, first of all, as people.
- To experience love and friendship.
- To experience continuity in their lives, especially in relation to the people who are important to them.
- To be respected and treated with dignity.
- To have access to opportunities and information, to make choices, and to exercise their rights.
- To learn those skills which are needed to participate, as much as possible, as valued members of their community.
- To have a decent and appropriate place to live.
- To have meaningful employment and contribute to the community.
- To have opportunities to continue to learn throughout their lives.

In a similar vein, William Allen's (undated) Read My Lips: It's My Choice, also developed under the auspices of the Governor's Planning Council in Minnesota, describes consumer-based needs assessment, developing consumer-based service plans, methods of consumer-based evaluations, and ideals on making the service system understandable. This booklet includes consumer-based evaluation for residential areas, worksites, staff evaluations, IPP checklist, a quality of life survey, and self-advocacy objectives. Items are presented in a straightforward format such as:

> Where do you go in the community? How do you get there? When? How often?

For assessment and planning purposes many relevant examples are provided. For community strengths, for example, a list of possible places such as video stores, sit down restaurants, shopping malls, and swimming pools is included.

Allen's Quality of Life checklist also includes some observational measures that may enhance the information obtained with direct interview scales. The checklist includes items such as: "Yes or No: The house is near other houses where people live."

IMPLICATIONS FOR CONSUMERS

Consumers are entering a new era of empowerment and a chance to realize their full potential through directing service providers to meet their individually defined needs. Consumers will go through periods of transition and will in some cases continue to need the assistance of advocates to help them through the maze of regulations and inter-agency domains that are hindering needed service provision.

At long last, consumers may be in a position to live lives according to the rhythm of everyday experiences, living as "persons" in the community, not as "clients" or "patients" or even "consumers", but rather as individuals.

IMPLICATIONS FOR STATE AND FEDERAL AGENCIES

As Bob Dylan has sung, "The times, they are achangin'."

It appears that consumers will achieve that which professionals have not--consumers will demand a more responsive funding structure, and rehabilitation providers will need to "explore new service strategies and develop new ways of thinking and acting." (Governor's Planning Council on Developmental Disabilities, 1987)

IMPLICATIONS FOR REHABILITATION SERVICE PROVIDERS

NARF has reiterated its views concerning directions for the next few years many times, through such statements as:

> The bottom line with quality for people who have led restricted lives involves expanding their environmental control, social interaction, and access to the community. (NARF, 1988, p.7)
>
> Facilities also will gain the competitive edge and enhance their credibility through increasing empowerment and providing opportunities for better wages and better working conditions... Facilities have an obligation to continue to do what they have done well and to improve those things they can do better. (NARF, 1988, p. 15)
>
> NARF's vision is that quality services will mean better lives for all and that NARF's research, networking, legislative efforts, and information dissemination will assist in achieving these quality outcomes. NARF's vision is "quality through quality..." (NARF, 1989a, p. i)

NARF is in agreement with the principles of consumer choice and consumer satisfaction. NARF has been a primary supporter of the Americans with Disabilities Act. Rehabilitation

facilities, like businesses, education, consumers, and the general populous are undergoing changes.

We are living in a time of rapid change. **As Tom Peters indicates, the best way to proceed is to learn to adapt quickly to change, to live with change, and accept it as a way of life.**

PRACTICAL CONSIDERATIONS: MEASUREMENT AND QUESTIONS TO ASK

The results of NARF's survey of supported employment providers (NARF, 1989c), provide reasons for immediate concentration on quality of life issues. Wide differences in costs and cost effectiveness, lack of overall provision for fringe benefits, and the substantial numbers of individuals employed part time which were reported in that study of 2,034 agencies all suggest that employment and integration alone have not yet introduced the empowerment that is possible. **Dialogue with consumers and a better understanding of their needs and concerns, including more joint planning, is needed.**

An examination of society at large provides sufficient evidence of the lack of empowerment when employed at minimum wage, without benefits, on a part-time basis. As with other studies on generalization (Ford & Mirenda, 1984; Freagon & Rotario, 1982; McDonnell & Ferguson, 1985; Wehman, Renzaglia, & Bates, 1985), if persons with severe disabilities are to be empowered, there exists a need to focus training and monitoring on empowerment in particular settings, under particular conditions, followed by systematic planning for generalization.

Given that consumers want significant input and decision making authority regarding their lives, how can the service sector facilitate such practices? **On a global level, the answer is simple and direct: get consumers involved.** On an individual level, consumer awareness and consumer communication skills vary widely. Service providers are obligated to assist consumers in their expression of individual needs and concerns. A place to start is with consideration of issues and concerns of value to each of us.

Mukherjee (1989) has provided valuable information on quality of life surveys for the general population. While some of the suggestions are more relevant for an East Indian culture, others seem quite applicable to the Western world. They include finding out:

- What do you want most in your life?
- What do you feel the lack of most in your life?
- What do you detest most?

- What do you want most to improve your life at work?
- What do you want most to improve your family life?
- What would you like most to be removed in order that you may improve your family life? Your work life?
- What would you like most to improve your neighborhood conditions?
- What do you want most for recreation and leisure?
- What is the goal in your life?
- What kind of support do you require to remove obstacles to this goal?
- What do you want most for a peaceful, happy, and progressive life?

Research on life and work satisfaction of non-handicapped persons (Hackman & Suttle, 1977; Moseley, 1988) indicates that social integration, growth and security, the development of human capacities, autonomy, the total life space, social relevance of work, adequate and fair compensation, and safe and healthy environments all contribute to one's quality of life. Job satisfaction also appears to be related to: supervision, job/task variety, recognition and praise (Calkins and Walker, 1990).

One attempt to use information regarding quality of life for persons without disabilities to develop QOL measurement for individuals with disabilities has involved field testing the Quality of Life Questionnaire (Keith, Schalock, & Hoffman; 1986) with over 500 persons in the United States, Israel, Germany, and Australia. From the field testing, four quality of life factors have emerged empirically: satisfaction, competence/productivity, empowerment/independence, and social belonging/community integration. The recent update of that instrument: The 1990 Quality of Life Questionnaire (Schalock, Keith, & Hoffman; 1990) includes two years of development work with 870 adults in the United States, Australia, Germany, Israel, and the Republic of China. That instrument includes standardization data across the same four areas according to four levels of disability and individual standardization across nine demographic variables.

As a part of its study of the relationship between supported employment program variables and quality outcomes for consumers, the National Association of Rehabilitation Facilities during 1989 completed a review of exemplary supported employment practices. From a total of 183 nominations, eight programs were selected for site reviews. As a part of that review NARF used both the Quality of Life

Questionnaire--the 1988 Field Test Version (Schalock et al., 1990) and NARF's modification--the Expanded Interview Form for persons with limited verbal skills. (NARF, 1989b)

Thus far, NARF's interviews with consumers--interviews conducted using the Expanded Interview Form--indicate that:

a. **Persons with severe disabilities and limited verbal skills have little direct input** into many decisions regarding quality of life issues and priorities.

b. **Many agencies address wages, hours worked, community integration, and benefits but do little beyond that to assist persons with disabilities to improve their quality of life.** Issues such as empowerment, choice decision-making, community utilization, environmental control, and friendship development are rarely assessed and plans for improvement are minimal.

c. **Systematic procedures for measuring quality of life and using those data for program planning are needed.**

d. **Some supported employees lack a "work related" vocabulary.** While these consumers may have limited verbal skills, they could receive instruction which would assist them in interacting with others. This instruction could include information on:

    - Where they work
    - The type of work they do
    - How many days a week they work
    - How many hours a day they work
    - Who is their supervisor
    - How they get to work
    - What time they get up to get to work on time
    - Whether they have vacation or other benefits
    - How long they have been working
    - What they like best about their job

By interviewing the individual with the job coach present, NARF reviewers were often able to obtain this information from the individual consumer.

NARF also has developed a draft version of the Consumer Job Satisfaction Scale (NARF, 1990) based upon the interviews

conducted for the exemplary practices review, as well as the factors contributing to quality of life for non-handicapped persons. See Fig. 1 for sample items from that Scale.

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2. Tell me more about your work. What do you do each day?

3. What is the name of the company (business) you work for?

5. How did you get this job?_____ Why did you decide to work here?

12. What is the hardest part of your job?
What happens if you make a mistake?...

14. Are you doing the type of work you want?

21. Would you rather work somewhere else?_____ Where?

Fig. 1 Items from the Consumer Job Satisfaction Scale (NARF, 1990)

Although the Consumer Job Satisfaction Scale was designed primarily to be used with individuals with cognitive impairments and limited verbal skills, an appendix includes suggested modifications for other disabilities. Figure 2 contains a sample of those modifications.

Substitute Items

10. What kind of support services do you receive and how often? Does your support person visit your work site? Is that okay or would you prefer to meet elsewhere?

Additional Items

E. How does your disability affect your job and your employment record?

F. How does your current job compare to past experiences?

G. Have you had any major problems with this current job? How were they handled? How do you feel about that?

Fig. 2 Sample Items from Appendix of the Consumer Job Satisfaction Scale

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NARF will be field testing the Consumber Job Satisfaction Scale during the coming year. NARF also plans on developing a branched interview format to assist with obtaining more detailed answers for items of particular relevance to the individual.

In regard to quality outcomes for consumers, NARF's review of exemplary programs revealed that most exemplary programs were:

- Working on career ladders and obtaining a variety of jobs that reflect the range of opportunities available in their local community.
- Locating jobs that paid at or slightly above minimum wage, with greater difficulty obtaining adequate hours and benefits.
- Achieving excellent physical integration, with social integration varying.
- Obtaining better job placements with the individual placement as compared to the group placement model.
- Only beginning to address consumer empowerment, control over wages earned, and other non-work quality of life issues. (NARF, 1989)

Additionally, discussions with others and reviews of the literature have revealed a paucity of information on the relative effectiveness of sheltered, supportive, and competitive employment on quality of life.

MEASURES OF SATISFACTION--INTEGRATING THE VERBAL AND NONVERBAL

Biklen and Moseley (1988) have suggested particular interview techniques to use with individuals with severe disabilities. When interviewing these persons, Biklen and Moseley emphasize the need to observe the individuals for acquiescence responses or attempts to please the interviewer; misunderstandings; the "same answer" or perseveration in responding; and the possible assistance provided through interviewing through significant others or breaking the question into component parts.

Biklen and Moseley further caution interviewers to "avoid open ended questions" and instead provide alternatives to which the interviewee can respond.

When NARF conducted its interviews with persons with limited verbal skills, we found that an expanded format that

accommodated choice decision making or yes-no responding was useful. Examples of that format are provided in Figure 3.

26a. Are you doing the type of work you want? Would you rather work somewhere else? Where?

27. Whose choice was it for you to get a job? Yours? Your parents? The workshop's?

39. Does someone teach you about your job? Does someone teach you new things? Who shows you? Do you get the help you need?

40. Are you ever lonely? Do you miss your friends? If yes: When do you get lonely? At work? During the weekends? At night? Yesterday? Today?

Fig. 3 Examples of items from the Expanded Interview Form (NARF, 1989)

Another useful technique suggested by Biklen and Moseley is to **consider the immediate environment and the context of the questions. Appropriate stimuli may facilitate finding out about particular concerns**; i.e., school concerns might be best addressed at school, home concerns at home.

When NARF conducted it's Quality of Life interviews at the job site it appeared appropriate to ask work-related questions and interviewers reported some feelings of discomfort and difficulty in communicating regarding non-work related issues. This was resolved through focusing mainly on work issues, starting with job-focused discussions, and avoiding some of the more personal items from Schalock et al.'s Quality of Life Questionnaire.

Other procedures recommended by Biklen and Moseley include: observing over a period of time in varied settings, getting to know a person, and trying to interpret the person's responses to the environment. A better understanding of quality of life will be obtained by following these practices rather than relying on a single interview.

Summary

> Thus persons with disabilities are still often barred or limited from many basic day-to-day activities, independent decision-making and community settings we take for granted in our own lives. (Cashen, 1989, p.12)

Despite the preponderance of recent information suggesting the need for self-determination, recent discussions also indicate that people with disabilities are at least beginning to direct their own lives. Perhaps during the 1990s they will truly become the "masters' of their own fate."

As we end the era of protectionism, protectionism flanked by bureaucracy, and walk into the era of "rights, risks, and responsibilities" let's remember to assure the necessary safeguards are in place through talking with and listening to those we assist.

REFERENCE LIST

REFERENCES

Allen, W.T. (undated). Read my lips: It's my choice. St. Paul, MN: Minnesota-Governor's Planning Council on Developmental Disabilities.

Ames-Zierman, S. (April, 1990). "IMAGINE" - The 1990 report on people with developmental disabilities to governors, state legislators and the U.S. Congress: Implications for advocacy, consumer empowerment, and change. Paper presented at the 11th Annual International Conference on Developmental Disabilities conducted by the Young Adult Institute, New York.

Biklen, S.K., & Moseley, C.R. (1988). "Are you retarded?" "No, I'm Catholic: Qualitative methods in the study of people with severe handicaps. The Journal of The Association for Persons with Severe Handicaps, 13(3), 155-162.

Birenbaum, A., & Re, M.A. (1979). Resettling mentally retarded adults in the community--almost four years later. American Journal of Mental Deficiency, 83, 323-329.

Birenbaum, A., & Seiffer, S. (1976). Resettling retarded adults in a managed community. New York: Praeger.

Burchard, S.N., Hasazi, J.E., Gordon, K.R., Yoe, J., & Simoneau, D. (1986, September 15). Community living project. Progress report. Burlington: University of Vermont, Department of Psychology.

Calkins, C.F., & Walker, H.M. (1990). Social competence for workers with developmental disabilities: A guide to enhancing employment outcomes in integrated settings. Baltimore, MD: Paul H. Brookes.

Cashen, J.A. (1989, Nov.-Dec.). Commentary: The need for value-enhancement training and informal support systems. Quality of Care, p. 12, 10.

Coulton, C.J., Holland, T.P., & Fitch, V. (1982). Matching patients with community environments. Cleveland, OH: Human Services Design Laboratory.

Coulton, C.J., Holland, T.P., & Fitch, V. (1984). Person-environmnt congruence and psychiatric patient outcome in community care homes. Administration in Mental Health, 12(2), 71-88.

D'Aubin, A. (1989). People have to be listened to. Winnipeg, Manitoba: Coalition of Provincial Organizations of the Handicapped.

Farber, B. (1968). Mental retardation: Its social context and social consequences. Boston: Houghton Mifflin.

Ford, A., & Mirenda, P. (1984). A natural cues and corrections decision model. Journal of the Association for the Severely Handicapped, 9(2), 79-87.

Freagon, S., & Rotario, A.F. (1982). Comparing natural and artificial environments in training self-care skills to group home residents. The Journal of the Association for the Severely Handicapped, 7(3), 73-86.

Goode, D.A. (1988). Principles and recommendations from the quality of life project. Valhalla, NY: The Mental Retardation Institute, Westchester County Medical Center.

Governor's Planning Council on Developmental Disabilities, (1987). A new way of thinking. St. Paul, MN: Author.

Hackman, R.J., & Suttle, L.J. (1977). Improving life at work: Behavioral science approaches to organizational change. Santa Monica, CA: Goodyear Publishing Co., Inc.

Hawking, S.W. (1988). A brief history of time: From the big bang to black holes. New York: Bantam Books.

Heal, L.W. (1988). Evaluating residential alternatives. In L.W. Heal, J.I. Haney, & A.N. Amado (Eds.), Integration of developmentally disabled individuals into the community (pp. 211-225). Baltimore, MD: Paul H. Brookes.

Heal, L.W., Novak, A.R., & Chadsey-Rusch, J. (1982). Lifestyle satisfaction scale. Champaign, IL: University of Illinois, Department of Special Education.

Johnson, M.D., & Fawcett, S.B. (undated). Quality circles: Building partnerships between consumers and service agencies: A leaders guide. Lawrence, KS: The Research and Training Center on Independent Living at the University of Kansas.

JM Foundation, The Robert Wood Johnson Foundation, & The Pew Charitable Trusts. (1989). A special report to grantmakers on empowering people with disabilities. New York, NY: Author.

Keith, K.D., Schalock, R.L., & Hoffman, K. (1886). Quality of life: Measurement and Programmatic implications. Lincoln, NE: Region V Mental Retardation Service.

Landesman, S. (1986). Quality of life and personal life satisfaction: Definition and measurement issues. Mental Retardation, 24(3), 141-143.

Ludlow, B., & Herr, S. (1988). Advocacy and adult rights to habilitation. In B.L. Ludlow, A.P. Turnbull & R. Luckasson (Eds.) Transitions to adult life for people with mental retardation. (pp. 233-256).

McDonnell, J.J., & Ferguson, B. (1985). A comparison of general case in vivo and general case simulation plus in vivo training. The Journal of the Association for Persons with Severe Handicaps, 13(2), 116-124.

McFadden, D.L. (1990, April). The 1990s: New Horizons or Old Platitudes? Paper presented at the 11th Annual International Conference on Developmental Disabilities conducted by the Young Adult Institute, New York.

Moseley, C.R., (1988). Job satisfaction research: Implications for supported employment. Journal for The Association of Persons with Severe Handicaps, 12(3), 211-219.

Mukherjee, R. (1989). The quality of life: Valuation in social research. Newbury Park, CA: SAGE Publications.

National Association of Rehabilitation Facilities. (1988). Quality of life. Washington, D.C.: Author.

National Association of Rehabilitation Facilities. (1989a). Exemplary supported employment practices. Washington, D.C.: Author.

National Association of Rehabilitation Facilities. (1989b). Expanded Interview Form. Unpublished paper. Washington, D.C.: Author.

National Association of Rehabilitation Facilities. (1989c). Supported employment in context: NARF's national scope supported employment survey and policy implications. Washington, D.C.: Author.

National Association of Rehabilitation Facilities. (1990). Consumer Job Satisfaction Scale (Draft). Unpublished paper. Washington, D.C.: Author.

Nirje, B. (1990, April) Beyond normalization: providing human rights for people with developmental disabilities. Paper presented at the 11th Annual International Conference on Developmental Disabilities conducted by the Young Adult Institute, New York.

Nisbet, J., & Hagner, D. (1988). Natural supports in the workplace: A reexamination of supported employment. The Association for Persons with Severe Handicaps, (13)(4), 260-267.

Novak, A.R., Heal, L.W., Pilewski, M.B., & Laidlaw, T. (1980, May). Independent apartment settings for developmentally disabled adults: An empirical analysis. Paper presented at the meeting of the American Association on Mental Deficiency, San Francisco.

Perske, R. (1989). National conference on self-determination. St. Paul, MN: U.S. Department of Education, Office of Special Education and Rehabilitative Services in conjunction with the University of Minnesota Research and Training Center on Community Living and the Minnesota Governors Planning Council on Developmental Disabilities.

Posey, T. (1990). Guest editorial: A home, not housing. Psychosocial Rehabilitation Journal, 13(4), 3-4.

The Premier's Council on the Status of Persons with Disabilities. (1989). Towards a new vision of abilities in Alberta. Alberta, Canada: Author.

Ridgway, P.A. (Ed.) (1988). Coming home: Expatients view housing options and needs; Proceedings from a national housing forum. Burlingto, VT: Center for Community Change Through Housing and Support, University of Vermont.

Schalock, R.L., Keith, K.D., & Hoffman, K. (April, 1990). 1990 quality of life questionnaire: Overview and standardization information. Unpublished manuscript.

Schalock, R.L., & Start, JA. (1988). Identifying Programming Goals for Independent Living. In Ludlow, B.L., Turnbull, A.P., & Luckasson, R. (Eds.). Transitions to Adult Life for People with Mental Retardation--Principles and Practices (pp. 85-100). Baltimore, MD: Paul H. Brookes.

Schwier, K.M. (1990). Speakeasy: People with mental handicaps talk about their lives in institutions and in the community. Austin, TX: Pro-Ed.

Tashjian, M.D., Hayward, B.J., Stoddard, S. & Kraus, L. (1989). Best practice study of vocational rehabilitation services to severely mentally ill persons. Volume I: Study findings (Contract Number 300-86-0131). Washington, D.C.: Rehabilitation Services Administration, U.S. Department of Education.

Wehman, P., & Moon, S. (Eds.). (1988). Vocational rehabilitation and supported employment. Baltimore: Paul H. Brookes.

Wehman, P., Renzaglia, A., & Bates, P. (1985). Functional living skills for moderately and severely handicapped individuals. Austin, TX: Pro-Ed, Inc.

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